

Fetal Alcohol Syndrome Update

Winter 2003

Office of FAS, Department of Health & Social Services, State of Alaska

New Commissioner to Lead Health and Social Services

Following the November election of Frank H. Murkowski as our new governor, the process began to establish a new Cabinet, including the appointment of Joel Gilbertson as the new Commissioner of the Department of Health and Social Services. Commissioner Gilbertson most recently served as legislative director and counsel on Governor Murkowski's U.S. Senate staff managing policy on health and social services issues such as Medicaid, Denali KidCare, Medicare, Social Security and welfare reform. In addition, the Commissioner worked for the Center for Health Services Research and Policy, and the National Association of Social Workers where he assisted in the research and publication of a nationwide study on Medicaid managed care contracts. In discussions with the Commissioner, he indicates the new administration is committed to Alaska's FAS agenda and will continue to support appropriate funds to improve our system of services to individuals with FASD and expand our efforts to prevent the birth of children affected by prenatal exposure to alcohol. We welcome the new Commissioner and look forward to working with him as we move forward the state's agenda on FASD. Welcome! ✍



Commissioner Joel Gilbertson

Recap of FAS Summit 2002



Crowded halls at the Summit

The FAS Summit 2002 was a great success this year with more than 600 people from across Alaska, the lower 48 and Canada in attendance. This year's theme "Gathering Resources for Today and Tomorrow" set the tone for a variety of great presentations — including a large number of Alaskan experts in the field of fetal alcohol

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Next Summit Tentatively Scheduled for March 9–10, 2004

In response to the growing number of people attending the annual FAS Summit we are working on plans to move to a bigger space for our next event. In order to accommodate a move, we will no longer be able to hold the Summit in November and have selected March as a good alternative! Please mark your calendars now and plan to attend FAS Summit 2004 on March 9–10 in Anchorage!

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FAS Community Team Highlights

After more than a year of planning, community outreach, and clinic development, the Sitka Community FAS Diagnostic Team held their first two Diagnostic Clinics in November and December, and they anticipate holding ongoing clinics at least once a month. Team Coordinator Dyan Bessette reports that both of the first clinics have gone very smoothly, and the team is excited and pleased about the progress they have made. The diagnostic team, which is managed by the Sitka Southeast Alaska Regional Health Consortium (SEARHC), is composed of a variety of individuals representing a number of Sitka agencies. The Sitka team has an especially strong commitment from their school district, and can boast they have active participation from school Speech and Language Pathologist Suzan Hess and School Psychologist and Special Education Director Chris Voron. Additional team members include Occupational Therapists Kay Levenson and Charlotte Kimber, Clinical Psychologist Charlie Morgan, Psychiatrist Aryeh Levenson, Parent Navigators Rex Sharpe, Terri McGuire-Gurule, Cla Lynn Strothers, and Jeanette Cawyer, and Pediatricians David Vastola and Marty Grasmeder. To encourage broad support for their activities the Sitka team has initiated a unique approach to getting community involvement – they have developed an advisory board under the auspices of *Advancing Our Youth*, a local, broad-based community effort that developed out of a desire to better coordinate youth services in the Sitka community. By using the *Advancing Our Youth* project as an oversight entity, the Sitka team has an opportunity to educate and network with all youth service programs in the Sitka area, as well as receive guidance and feedback from a wide variety of agencies, making the Sitka team truly community-driven. For more information about the Sitka FAS Diagnostic Team, contact coordinator Dyan Bessette at (907)966-8629.✍

Alaska's Town Hall on FASD

The Town Hall Meeting on FASD brought forth testimony from across the state from parents, caregivers, judges, teachers, social workers, medical providers and young adults with FASD. Testimony was received from 56 individuals through in-person presentations at the Anchorage LIO, teleconferenced testimony from Barrow, Dillingham and Stuyahok, and written testimony via fax, e-mail and web-based submittal forms.

Testimony focused on the need for better training for all service providers, improved understanding of FASD for eligibility testing related to developmental disabilities and special education, and discussion related to the removal of IQ scores as a test for eligibility. The continuing need for respite care for families, better training for foster parents and better information sharing with foster/adoptive parents about the needs of children with FASD were also highlighted. Many families discussed the need for more focus on services for adolescents and adults with FASD, including supported living, job training/coaching and social and life skills development.

We extend a special thank you to the individuals who served on the panel hearing testimony including Ed Riley, FAS Center for Excellence;

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Karen Perdue, University of Alaska; Ed McLain, Department of Education and Early Development; Steve Warnke, Alaska Native Health Board; Representative Fred Dyson; Steve McComb, Division of Juvenile Justice; Judge M. Francis Neville, Alaska Court System; Michael Lesmann, Division of Family and Youth Services; David Maltman, Division of Mental Health and Developmental Disabilities; Melinda Freeman, Governor's Advisory Board on Alcoholism and Drug Abuse; Deborah Stone, SAMHSA, Center for Substance Abuse Prevention; and Sarah Williams, Department of Corrections.

All testimony will be transcribed and a written report of the highlights will be made available to all interested parties.✍

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spectrum disorders. Keynote speaker for the 2-day conference, Dr. Ed Riley, wowed the crowd with new brain images and research on the specific impacts prenatal alcohol exposure has on the developing brain. Other highlights included a young adult panel featuring Misty Ford of Dillingham, Rena Taaffe of Fairbanks, Jake Myers of Fairbanks, and was facilitated by Mary Lou Canney of the Resource Center for Parents and Children.

On Friday, the Summit Luncheon debuted the new RurAL CAP prevention video, "The Final Score, Winning Against FAS" to an appreciative audience, and highlighted how Alaskan agencies are emerging as leaders in the field of FAS. The luncheon ended with the awarding of the newly named "Carolyn and Arnold Wilson Award for Excellence in FAS Prevention and Advocacy" to Ardyce and Gary Turner from Bethel, long-time advocates, educators and parents of a child with FASD.

For the second year in a row, Summit participants received a "Summit Resource Book" – a compilation of resources and handouts from many of the conference presenters. The Office of FAS has a limited number of extra books available, and will distribute them on a first-come-first-serve basis. If you would like to request a Summit Book please contact the Office of FAS at (877) 393-2287.✍



Dr. Riley addressing the audience.



The Youth Panel discussing FAS during the Summit.



Ardyce and Gary Turner receive the 2002 FAS Award for Excellence.

Outreach Material Still Available

Copies of the posters, brochures and message pens, developed in conjunction with our public education media campaign are still available for distribution. We have just completed the third printing of the two brochures—*Healthy choices; healthy babies* and *Thankfully there are people who will help her; Are you one of them?* To date approximately 20,000 copies of these brochures and 1,000 posters have been distributed statewide. If you would like copies of the posters, brochures or pens just give us a call or e-mail your request to fas@health.state.ak.us.

Mini-Grant Applications Available

Stone Soup Group has released their application for one-time grant awards of up to \$3,500 for communities to host their own FAS Family Camp. Eligible communities are those that are served by a FAS Diagnostic Team. The grant application can be found on our web-site at www.hss.state.ak.us/fas. Applications are due by February 28, 2003. For more complete information contact Cheri Scott at 907-561-3701.

News from FAS Innovative Grantees

Norton Sound Health Corporation

Are the grantees in Nome so Innovative? We think so! The Norton Sound Innovative Grant has promoted outreach to regional communities and increased prevention efforts and support for the families in their region.

Recently the Nome FASD Resource Office combined efforts with the Maternal Child Health Department in the Norton Sound Regional Hospital. In this way, every time a woman from the region (of 8500 people in 16 villages) discovers she is pregnant and attends her first "OB", a brief substance use screening occurs. If the woman acknowledges substance use, a referral is made to the Nome FASD Resource Office. The identified woman is then contacted, and sent a "congratulations on your pregnancy" letter as well as a pamphlet about FASD. This effort has helped in identifying woman at risk as well as providing support for sobriety maintenance. To compliment this project, the Behavioral Health Services Outpatient Clinic now has a duplex to provide sober housing through the Healthy Paths Program. Healthy Paths will focus on services for women and children and will be up and running in early 2003.

In addition the project has partnered with mental health clinicians to provide "Student Support Teams" in the Nome elementary, secondary and high schools. These teams will provide behavioral intervention recommendations and strategies for students who are identified by teachers and parents as having challenging behaviors. One of the clinicians has a talented mother who loves to sew and is designing weighted animals to provide to students to assist them with their sensory integration issues. Additionally, team meetings provide the perfect opportunity to educate the teachers about the secondary disabilities associated with FASD.

Gateway Center for Human Services

The Gateway Center for Human Services Child and Youth Program has started a series of consultations with Kathryn Shea, MSW. The consultations are geared towards enhancing intervention strategies for children with special needs, such as fetal alcohol spectrum disorders (FASD). The purpose of this specific, ongoing training is to help clinical staff gain the knowledge, skills, and tools to move beyond traditional treatment strategies that have been targeted primarily at a child's presenting symptoms. Drawing from the Individual-Difference approach espoused by the internationally recognized developmentalist and child psychiatrist Stanley Greenspan, M.D., Ms. Shea is helping GCHS clinicians learn to assess and direct interventions towards the regulatory processes underlying a child's social, emotional, and behavioral problems.

GCHS clinical staff are learning to develop a regulatory profile of the way each child receives, processes, and responds to information from the world. According to the Individual-Difference approach to treatment, these processes form the structural foundation upon which all subsequent development is built. Within this profile is information about

a child's sensory reactivity, sensory integration and processing, muscle tone, and motor planning and sequencing. This information is then used to help build upon a child's strengths and bolster his/her weaknesses as a means of generating the capacity to remain calm, focused and interested in the world around them.

The clinical staff at GCHS are excited about the prospect of 'fine-tuning' intervention strategies that are aimed at the developmental source of a child's difficulties rather than treating the more visible behavioral manifestations.

Ms. Shea's enthusiasm for this cutting edge approach to treatment was evident during her FASD workshop in Ketchikan last year and the clinical staff anticipates the development of a quality service delivery track for children and youth with fetal alcohol spectrum disorders.

Rural Alaska Community Action Program, Inc. (RurAL CAP)

RurAL CAP's Early Decisions Project has been very busy announcing developing new materials to enhance the state's efforts to prevent FASD. First, they are pleased to announce that their new website has come online. It features information about their project and educational materials as well as links to other agencies that can provide more information about fetal alcohol syndrome. The form for ordering these materials is available online at www.earlydecisions.org.

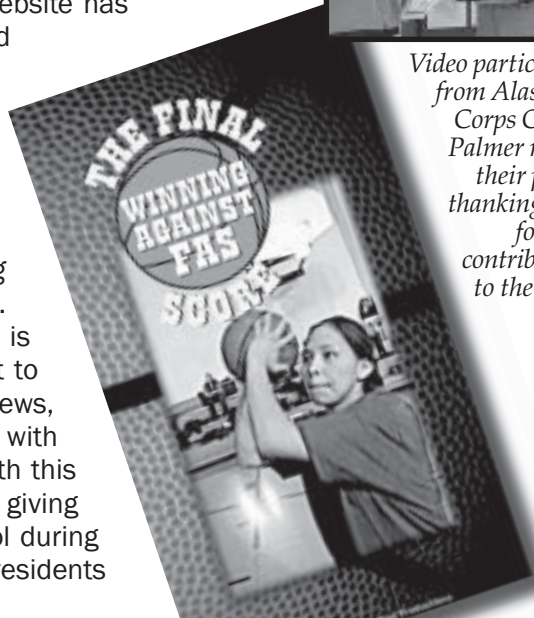
Making its debut at the FAS Summit 2002 was the much anticipated prevention education video for middle and high school students and young adults. *The Final Score: Winning Against FAS* is a 14-minute video aimed at preventing FASD. The story centers on a teenage girl who does not know she is pregnant and has to make a decision about whether or not to drink alcohol. In addition, the video includes several interviews, one with a mom who gave birth to a child with FAS and one with an adoptive mom who shares her story of raising a child with this disability. The video also features four Alaska Native elders giving advice to future child bearers about abstaining from alcohol during pregnancy. The video is available free-of-charge to Alaska residents and \$25.00 for anyone outside of Alaska.

To compliment *The Final Score* video, the Early Decisions project is in the process of creating a FASD prevention curriculum that integrates science, health and social studies into five teaching units. These teaching units will include lesson plans, activities, supplemental activities, overheads, power point presentations, additional resources, and the video and will be available for use in middle schools, high schools and other educational and health care settings.

RurAL CAP is looking for rural teachers and other educators to test pilot the curriculum and provide feedback about the curricula. If you are interested in test piloting the curriculum, please contact Monica Anderson (manderson@ruralcap.com) or Marian Estelle (marian@ruralcap.com) or call toll free in Alaska (800)478-7227 or (907) 279-2511.✍



Video participants from Alaska Job Corps Center-Palmer receive their plaque thanking them for their contributions to the video.



Walter Austin (left) and Rita Blumenstein (right) were two of the elders in the film who gave advice to future child bearers about abstaining from alcohol anytime during pregnancy.

Alaskan's Recognize International FAS Awareness Day

Communities across Alaska used September 9, 2002 to “get the word out” regarding the dangers of drinking alcohol during pregnancy and the resulting birth defects. International FAS Awareness Day was celebrated not just here in Alaska, but across the globe, as we marked the fourth year for this international awareness event that began when parents and caregivers of children, youth and adults with FASD came together to educate the world about this preventable disability.

In Alaska, communities from Kotzebue to Ketchikan developed unique and innovative ways to educate and inform people that during pregnancy, no alcohol should be consumed—not even a drop! Here are a few community highlights showing what a great job everyone did!

Kotzebue/Northwest Arctic Borough

On September 9th churches in the region were asked to ring their bells for one minute at 9:00 a.m. to remind people that drinking alcohol anytime during pregnancy is not safe. KOTZ Radio hosted a Morning Report at 8:30 a.m. featuring the FAS Diagnostic Team Coordinator Jeanne Gerhardt-Cyrus and parents Amelia and Dan Davis. This allowed the regional team to talk about their newly developing services, and to publicize their upcoming Parent Conference. The Maniilaq Health Center passed out prevention messages to all lunch customers both in the cafeteria and on patient trays as well! The Empress Restaurant in Kotzebue also included prevention messages with all orders throughout the day. In conjunction with FAS Awareness Day the local FAS Team hosted a two-day parent conference “Building Support for Families and Caregivers of Children and Adults Affected by Prenatal Exposure to Alcohol.”

Nome

In Nome the FAS Diagnostic Team took the lead in recognizing and celebrating International FAS Awareness Day. A variety of activities took place including the distribution of educational flyers throughout Nome and an announcement about FASD and upcoming activities in the Nome Nugget, the areas weekly newspaper. The local hospital participated with a FASD informational bulletin board in the main hall of the hospital, an inter-hospital e-mail notifying people of FAS Day and its activities, and a FASD Open House with cake and information in the hospital cafeteria—over 60 adults and 12



Andrea Longpre-Macht reading to children at the FAS Day Open House in Nome.

children attended. The local radio station KNOM did a wonderful “profile” of Andrea Longpre Macht, Coordinator for the local FAS Diagnostic Team, airing it twice on September 9th.

Copper Center

The Copper Center area FAS Diagnostic Team utilized both the distribution of educational materials and the local radio station to distribute information about FASD across the region. On the Monday following FAS Day Cheri Scott, Parent Navigator from Stone Soup Group in Anchorage, traveled to Copper Center to work with the Diagnostic Team and she and Gay Wellman, Team Coordinator participated in a 1-hour radio talk show transmitted to Valdez, Cordova, Whittier, Fairbanks and surrounding communities. In addition, they had Cheri do a 5-minute interview for use the following day for their morning news feature.

Anchorage

FAS grantees in the Anchorage area combined forces to inundate the community with information, activities and projects aimed at raising awareness about the dangers of drinking during pregnancy and steps to take to encourage prevention of



Youth in Action passing out FAS knots.



Youth in Action tying FAS knots.

FASD in the future. RurAL CAP, Salvation Army's Booth Memorial Home, Volunteers of America, the Stone Soup Group and a number of Southcentral Foundation's programs including Dena A Coy, Prenatal Support Services, FAS Diagnostic Clinic, and Pathway Home worked together to organize a full day of activities. From the local community the Youth-In Action program, a student chapter of MADD, the Closed Treatment Unit at McLaughlin Youth Center, and members of the Alaska Women's Recovery Project also actively participated in the day's events.

Prior to September 9th members of the Youth-In Action program and youth from McLaughlin Youth Center did a great job preparing awareness materials including tying hundreds of FAS knots! The Alaska Women's Recovery Project worked with area grantees to recruit local coffee shops and restaurants to participate by placing FAS awareness stickers on their to-go coffee cups and offering free non-alcoholic drinks to pregnant women throughout the day. Many thanks to the participating businesses including J & J Concessions, the Coho Cup, Kahladi Brothers Coffee, Jitters, Bulldog Coffee, Iron Horse Express and the Moose's Tooth and Bear Tooth restaurants.

The morning began with the reading of a Mayoral Proclamation by Mayor George Wuerch and bell ringing by several local churches. The day ended with a community-wide FAS Awareness Day event at RurAL CAP, premiering the new FASD prevention video *The Final Score: Winning Against FAS*, a product of RurAL CAP's Early Decision's project. Over 100 people attended with the video cast and crew receiving recognition for their hard work and commitment to make the video a success—T-shirts, certificates and plaques were presented to the Alaska Job Corps Center in Palmer and the Salvation Army Booth Memorial Youth & Family Services program.

One especially touching activity was the joining together of the SCF Pathway Home youth residents with

the women in recovery at Dena A Coy. In recognition of FAS Awareness Day the youth attended a lecture about FAS, learned about the treatment program for women at Dena A Coy and then made banners and wrote notes to the women, encouraging them in their sobriety. The day ended with the women at Dena A Coy sharing how alcohol and the effects of FAS had impacted their lives and the lives of those they love. By all accounts it was a moving, insightful and powerful day for youth and adults alike.

Kenai

The Kenai Peninsula FAS Diagnostic Team made and distributed 2,500 FAS Awareness Day information cards with attached FAS Knot pins. The cards were distributed to area businesses, physician offices, schools and human service agencies. Two families living with FASD from Seward and Homer were interviewed for feature articles in the Seward Phoenix Log and the Homer News. Letters to the Editor were sent to area newspapers thanking the many volunteers who made the FAS knots, outlining their significance. Lori Evans, Editor in Chief of the Peninsula Clarion wrote a wonderful editorial about FASD and the work being done on the Peninsula to prevent FASD and to improve services to local families. Public Service Announcements developed by the Kenai Team were distributed to local newspapers and radio stations highlighting FAS Awareness Day and its importance. In addition, Mayors David R. Carey of Soldotna, Edgar Blatchford of Seward and John J. Williams of the City of Kenai all issued proclamations recognizing International FAS Awareness Day.

Nanwalek

The Chugachmiut Healthy Start project sponsored a *Teddy Bear Picnic* for all the babies born in the last year in the community of Nanwalek. All of the families had received prenatal support services through the clinic and the project and the picnic provided a time to celebrated the good health of the babies and the sobriety of the families—prevention of FASD at its best! ✍



Nanwalek's Teddy Bear Picnic celebrating healthy babies.

Coming Soon... FY04 Grant Applications

Beginning in January, the Office of Fetal Alcohol Syndrome, along with other Department of Health and Social Services divisions, will begin releasing FY04 Request for Proposals (RFP) for a variety of department-wide grants. For a listing of grants for all departments, please visit the online public notice section of the state web page at <http://notes3.state.ak.us/pn/pubnotic.nsf>.

The Office of FAS will be releasing several RFP's for new programs. Approximately \$500,000 will be available for new innovative grant projects that should focus on enhancing and expanding services for prevention of fetal alcohol spectrum disorders (FASD) or services for those affected by FASD. Almost \$900,000 will be available to continue successful existing innovative projects that offer services for parent support, family camps, trainings on FASD, respite care and prevention materials.

Other RFP's being released will seek proposals for pilot projects for in-state diagnostic training, life-skills training and services for adolescents and young adults with FASD, and an advocacy and prevention program for working with new mothers recovering from alcohol abuse. Team development grants will also continue for our 13 Community Diagnostic Teams.

For questions about upcoming grants, please contact Jenny Huntley, Grants Administrator for the Office of FAS, toll-free at (877) 393-2287.

FAQ: What are the Characteristics of Women Giving Birth to Children with FASD?

When asking this question the issue we are really trying to understand is "how can we better identify high-risk women and prevent all fetal alcohol spectrum disorders?" Because prevention of FASD is our most important priority, it is vital that we have as much information as possible to give us the tools to intervene and support high-risk women with a thoughtful, well planned approach.

During the past five years much research has been done to look at the characteristics of women giving birth to children with fetal alcohol spectrum disorders, as well as the overall drinking patterns among women of childbearing age. It is important to remember that drinking of alcohol among all women who have the potential to become pregnant is an issue we need to focus on in terms of primary prevention. In a recently released report from the Centers for Disease Control and Prevention (CDC), they found that:

*"During 1991–1995, alcohol use by pregnant women increased substantially, and alcohol use by nonpregnant women of childbearing age increased slightly. Since 1995 the rate of **any** alcohol use during pregnancy (at least one drink) has declined. However, rates of binge drinking (more than 5 drinks on any one occasion) and frequent drinking (more than 7 drinks per week) during pregnancy have not declined, and these rates also have not declined among nonpregnant women of childbearing age." "Alcohol Use Among Women of Childbearing Age—United States, 1991–1999,"*

MMWR, April 12, 2002

Additional information in this report, which Alaska data also corroborates, is the fact that pregnant women who are unmarried and older (30 years and older) tend to have the highest rates of alcohol use. In the CDC report, binge drinking and frequent drinking during pregnancy were more common in women aged 30-44 years, but among nonpregnant women, these drinking patterns were more likely to occur among women under 30 years of age. In addition, it finds that heavy alcohol use before pregnancy, especially among older women, is a clear indicator that drinking will continue during pregnancy.

Data collected by the Alaska FAS Surveillance Project provides a similar picture of the mothers of children with FASD who have been reported to the Alaska Birth Defects Registry. For mothers with children born in 1995-1998, whose children were identified as prenatally exposed to alcohol, most (over 60%) were 30-39 years old at the time of the identified birth. These mothers were generally single, had an average of 2.8 prior births, over 75% smoked tobacco and at least 20% had received alcohol treatment at some point during their lifetime. It is also important to know that 15% did not receive any prenatal care during the pregnancy and when prenatal care did occur it usually began in the second trimester.

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In a study led by Dr. Susan Astley, University of Washington, results show a number of commonalities with what we have already seen regarding age, prior births, past drinking history, etc. What this report also shows is the mental health profile of the women in their study, as well as the adverse experiences these women had during their lifetime.

"Ninety-six per cent had one to 10 mental health disorders with the most prevalent being post-traumatic stress disorder (77%) and simple phobia (44%)." In addition, 98.8% reported being emotionally abused as a child and 95% reported being sexually and/or physically abused at some time during their life. "Fetal Alcohol Syndrome (FAS) Primary Prevention Through FAS Diagnosis: II. A Comprehensive Profile of 80 Birth Mothers of Children with FAS."

Alcohol & Alcoholism Vol. 35, No. 5, pp. 509-519, 2000.

Preventing prenatal exposure to alcohol is one of our state's top priorities. Having as much research-based and anecdotal information as possible to help us more clearly understand the barriers and struggles that women face, will provide us with the knowledge we need to develop better and more effective intervention and prevention strategies for our state. ✍

New Report on Special Education

On July 1, the President's Commission on Excellence in Special Education submitted its final report to the White House—"A New Era: Revitalizing Special Education for Children and their Families." The report responds to President Bush's charge that the Commission study issues related to federal, state and local special education programs in order to improve the educational performance of students with disabilities. This report represents the thoughts, recommendations and wisdom of more than 100 recognized special education experts, education finance experts, education and medical researchers, parents of children with disabilities, individuals with disabilities and others with expertise in the field of special education. In addition, the Commission heard from hundreds of other individuals and organizations at 13 public meetings held in cities nationwide.

One interesting recommendation from this report is the elimination of using IQ scores as a baseline for eligibility for special education services—

"There is no compelling reason to continue to use IQ tests in the identification of learning disabilities. And, if we eliminated IQ tests from the identification of individuals with learning disabilities, we could shift our focus on to making sure that individuals are getting the services that they need and away from the energy that's going into eligibility determination."

Sharon Vaughn, Ph.D.

Copies of this report are available online at www.ed.gov/inits/commissionsboards/whspeiaeducation/ or you may order copies at www.ed.gov/pubs/edpubs.html. ✍

Helping Youth Transition from Foster Care to Independent Living

The DHSS Division of Family and Youth Services announces a new way to help young people in foster care prepare for life on their own. Independent living funds are available through DFYS for youth 14 and older, in state custody, as they prepare for transition from foster care to self-sufficiency. Funds may be used to obtain skills such as time/money management or cooking and cleaning; experience, such as education or vocational training; or materials, such as textbooks and household items to achieve self-sufficiency.

Two conditions for funding are: 1) The request must be consistent with the child's case plan; 2) The child must have completed the Ansell-Casey Life Skills Assessment (ACLSA) and the results must be in the case file.

For more information contact Deirdre O'Connor, DFYS Independent Living Coordinator, at (907) 465-3209 or online at www.state.ak.us/dfys/independentliving/.

Welcome Thea...

Thea Howard has joined the staff of the Office of FAS as our new Statistical Clerk. We are very pleased to have Thea as a staff member, providing data entry and assessment for our increasing pool of numbers, data and information! Thea has a B.A. degree in Psychology from Barnard College of Columbia University and served as a research assistant at Teachers College working on a national longitudinal study of children and how their environments impact their educational outcomes. Thea's first project is to complete the data entry for our recently administered KABB survey—abstracting data from over 3,000 completed surveys.



Thea Howard

The Affects of Prenatal Alcohol Exposure on Vision

Dr. Charles Jaworski, Director of Eye Care for Norton Sound Health Corporation in Nome, literally opened our eyes at the 2002 FAS Summit in Anchorage. His presentation entitled, "The Effects of Fetal Alcohol Spectrum Disorders on the Eye and Visual System" caused quite a stir. According to Dr. Jaworski, the eye is formed from brain tissue as early as the 27th day after conception. Anything that can affect the brain embryologically (e.g. alcohol) can have significant effects on the eyes and visual system.

Visual perception is the ability to make sense of the visual world, combine visual information with other senses and functions, and use this information to effectively interact with the world. An individual with prenatal alcohol exposure may have any number of visual problems that directly result in the common behaviors we see due to their attempt to adapt and possibly overcompensate for their visual limitations.

Without intervention and correction, the eye can develop amblyopia, also called "Lazy Eye". This is an active neurological process in response to unacceptable visual problems such as double vision, confusion, deprivation, etc., and it takes away already limited resources of a damaged brain. It can usually be effectively treated if caught early. This is very critical in children with FAS as they already have limited neurological resources. Therefore, the sooner an accurate diagnosis of visual impairment, the better!

Dr. Jaworski suggests that "an eye doctor should be a part of any FAS diagnostic team" because eye exam findings are often very specific for FAS and are invaluable if the diagnosis of FAS is in question. Eye exams are mostly non-invasive, easy to do and relatively inexpensive (often covered by insurance). And many of the eye problems can be fixed or managed. Unlike many of the other problems associated with FAS, there are effective treatments and interventions in eye care that can significantly increase a child's functional ability.

For instance, nystagmus is the development of jerky, uncontrollable eye movements that are indicative of neurological damage and can result in reduced vision (squinting, accident prone children). Binocular disorders occur when eyes have a difficult time working together, resulting in poor visual performance in tasks such as reading or sports. This disorder is very common with fine motor difficulties (child blocks one eye when reading). Strabismus occurs when the eyes do not point

"The optic nerve is not a nerve, it's a track of the brain, same as the corpus callosum" ...**WHAT?**

"The retina is made of brain tissue and the rods and cones are neurons" ...**WHAT?**

No wonder 90% of children with FAS have specific ocular problems!

to the same area at the same time (cross or wall-eyed). This results in spatial localization dysfunction. Some studies show that 100% of people with FAS have high corneal curvature. This causes refractive errors in the eye such as near and far sightedness (easily fixed with eyeglasses or contact lenses). Optic nerve hypoplasia is the underdevelopment of the optic nerve, part of the underdeveloped brain. This almost always reduces the vision in one or both eyes.

With this information, new options are now available to improve services to individuals with FASD and visual difficulties. Thank you Dr. Jaworski! ✍

FASD Training Becoming More Accessible for Educators

The Department of Education and Early Development has created a series of e-learning modules to provide ongoing and sustained professional development for special education paraprofessionals seeking to satisfy the 6-hour annual training requirement. Through a collaborative effort between the Health Promotion and Special Education units at the Department of Education and Early Development a FASD e-learning training module is currently being developed, and is anticipated to be completed by early spring of 2003.

The FASD e-learning training module, like the other e-learning modules, is being created by the vendor, KnowledgeNet. Courseware developers, graphic designers, and subject matter experts are joining efforts to create an instantly accessible FASD resource for educators. The e-learning module will contain engaging animations that serve as “visual sentences” to illustrate key concepts, as well as audio narration for all of the content in the course to make it easily understandable for all types of learners. The e-learning module will review FASD definitions and associated brain differences, common learning needs, offer teaching strategies that may be helpful, and outline frequently effective environmental accommodations. Pre-tests and post-tests will be incorporated to measure each learner’s knowledge and to offer prescriptive learning options.

The Paraprofessional Training Program is available 24 hours a day, seven days a week, through EED’s branded on-line campus environment. While the e-learning modules have been created specifically to support paraprofessionals, they are accessible to all teachers, parents, and other interested parties. Indeed, these modules are accessible to anyone with Internet access free of charge. For those without Internet access, CD-ROM versions of the modules will be made available through EED. Finally, the e-learning courses are being offered for credit to paraprofessionals through an agreement with Alaska Pacific University. For more information contact Todd Brocious, FAS Education Specialist at (907) 465-2825 or e-mail inquires to todd_brocious@eed.state.ak.us ✍

A Sad Good-bye to our Friend and Colleague

On Saturday, October 19, 2002 Connie Merrigan, our friend and colleague, passed away suddenly leaving tremendous emptiness and sorrow in our hearts. Connie was a dedicated member of our FAS Evaluation Team, working specifically on the collection of data and analysis of our community-based FAS Diagnostic Teams. Connie had traveled to visit most of our 13 Diagnostic Teams, developing a monograph for each program outlining how the team was structured and functioning. Along the way she made friends with everyone she met. In addition, Connie was responsible for the input and analysis of the quarterly data collected by each of our teams regarding number of diagnoses, demographics of clients and diagnostic categories. Connie had achieved a major break-through in helping our grantees understand and value the important benefits of the data they were collecting. Connie’s enthusiasm and excitement for life was infectious and we miss her more than words can say.



Connie and Cowboy

Dates to Remember

FAS Update/Winter 2003

February

17–19, **Alaska Statewide Special Education Conference. Present Goals...Future Successes.**

Location: Anchorage Sheraton Hotel. Pre and Post conference activities will take place Feb. 15–16 and 20–21. For information call The Coordinators Inc., (907) 646-6000.

20–22, **FAS and Other Drug Related Effects: Doing What Works.** Sponsored by FAS Support Network of British Columbia. Location: Coast Plaza Hotel and Suites, Vancouver, BC, Canada. (604) 822-4965 or interprof@cehs.ubc.ca or www.interprofessional.ubc.ca.

21–22, **Eye of the Storm.** Presenter: Deb Evensen, Location: Edgewater Inn, Seward, Alaska. Sponsored by Frontier Community Services and FAS Diagnostic Team.

For more information call Vickie or Margaret at (800) 819-8194 or (907) 262-6331

April

22–23, **Early Childhood Behavioral Health Institute.** Location: Anchorage Hilton Hotel. For information contact Kathy Allely, (907) 269-5231 or kathy_allely@health.state.ak.us.

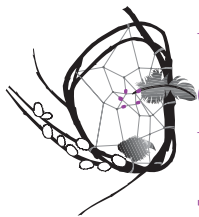
24–25, **Full Lives: Moving Forward Together Direct Support Conference—2003.** Location: Marriott Hotel, Downtown Anchorage. For information (907) 272-8270 or www.alaskachd.org/fulllives/.

May

5–7, **Annual School on Addictions: Serving the Whole Person.** Sponsored by the Substance Abuse Directors Association of Alaska. Location: Sheraton Hotel, Anchorage. For information contact SADA, (907) 770-2927 or www.meetingresults.com/projects.php.

June

2–6, **Annual Rural Provider's Conference.** Location: Seward, Alaska. For information contact Marian Estelle, RurAL CAP, (800) 478-7227 or www.ruralcap.com.



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